

January 22, 2014

This is The Arc's second commentary on the Draft 1115 Medicaid Waiver. The Arc's comments submitted on November 20, 2013 remain relevant. We also appreciate the attention and changes in the new draft which resulted from comments from the Developmental Disability Advocacy Community. Thank you.

Our commentary on this new Draft 1115 will concentrate on six key areas of Pathway 5: LTSS Infrastructure, Choice, and Coordination:

1. Ligas Consent Decree
2. Bogard Consent Decree & Free Standing Non-Conflictual Service Coordination
3. New Centers For Medicaid & Medicaid Services New Rules on Home & Community Based Services
4. Governor Quinn's Rebalancing Initiative
5. Recommended Two New Waiver Goals
6. Other
7. Arc Position on Service Coordination

**LIGAS CONSENT DECREE.** The Ligas Consent Decree has had a major positive impact upon the Illinois Developmental Disability System, and the submission of a new 1115 Medicaid Waiver needs to embrace the tenets of this extremely important Decree. The Decree is moving Illinois' highly institutional system into Home & Community-Based services in the most integrated setting by moving over 600 individuals out of ICFDD's last year. The Decree is moving Class Members off the PUNS Waiting List: 1,500 last year alone. These efforts must continue and expand. In this next year, greater attention needs to be focused upon the quality of community based services including person centered planning, smaller community living options, employment and flexible day services/supports. A new Case Management initiative has recently been launched which will streamline practices and create consistency in the intellectual disability systems processes across the state. These efforts must continue and the current Free Standing Non-Conflictual Independent Service Coordination needs to be maintained in the new 1115 Medicaid Waiver.

**BOGARD CONSENT DECREE.** The Arc and the State reached agreement with the Bogard Consent Decree. This Decree established Free Standing Non-conflictual Independent Service Coordination within the Illinois Developmental Disability System. The Arc expects the current Free Standing Non-Conflictual Independent Service Coordination to be maintained and enhanced within the new 1115 Medicaid Waiver.

**NEW CMS RULES FOR HOME & COMMUNITY BASED SERVICES.** The new CMS Rules on Home & Community Based Services need to be fully incorporated into the new 1115 Medicaid Waiver. Those key provisions, published in the Federal Register on January 16, 2014: <https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

The final rule requires that all home & community based settings meet certain qualifications including:

- The setting is integrated in and supports full access to the greater community;
- Is selected by the individual from among setting options;
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizes autonomy and independence in making life choices; and
- Facilitates choice regarding services and who provides them.

The final rule also includes additional requirements for provider-owned or controlled home and community-based residential settings. These requirements include:

- The individual has a lease or other legally enforceable agreement providing similar protections;
- The individual has privacy in their unit including lockable doors, choice of roommates and freedom to furnish or decorate the unit;
- The individual controls his/her own schedule including access to food at any time;
- The individual can have visitors at any time; and
- The setting is physically accessible.

Any modification to these additional requirements for provider-owned home and community-based residential settings must be supported by a specific assessed need and justified in the person-centered service plan.

The new rules places greater emphasis on providing community day services in the most integrated settings and also call for Non-Conflictual Case Management.

**GOVERNOR QUINN'S REBALANCING INITIATIVE.** In concert with the Ligas Consent Decree, the Governor's Rebalancing Initiative is dramatically enhancing the Developmental Disability System. The 1115 Medicaid Waiver needs to embrace this important Initiative by continuing to close wasteful, antiquated state institutions and invest in home & community based services/supports with continued emphasis upon person-center planning, employment and flexible day services. The Arc would recommend that all state institutions be closed by 2019.

## RECOMMENDED TWO NEW 1115 WAIVER GOALS.

1. By 2019, all Community Living Options shall be four persons or less within the Illinois Developmental Disability System.
2. By 2019, all state institutions in Illinois will be closed.

## OTHER

1. The Universal Assessment Tool that determines eligibility for the proposed new waiver is a key element of the waiver and as such it would be helpful to know who will be designing it and how it will differ from the way individuals are currently assessed under the multiple waivers we have now.

2. Health Care & Family Services is a small agency with many things on its plate. Current waivers are the responsibility of multiple agencies. How does the 1115 waiver application address the ability of HFS to administer the new waiver?

3. We are concerned about the expansion of the use of Managed Care Organizations in the Medicaid service delivery model for Illinois, especially in the social services arena where they have little expertise. The application lacks detail about the role of MCOs and, in particular, we oppose the use of MCOs in the approval or delivery of home and community based services to persons with intellectual or developmental disabilities.

4. The application mentions "supported employment" as a service included in the waiver. The power point refers to services supporting integrated competitive employment. Illinois is now an "Employment First" state, which the Arc of Illinois strongly supports. Specifically, how will the new waiver foster the implementation of Employment First in Illinois to address the needs of persons of varying abilities, skill levels and ages?

## THE ARC'S POSITION ON SUPPORT COORDINATION

### *Support Coordination*

Support coordination is critical for finding and coordinating the necessary services, supports and resources within the community that are required by children and adults with intellectual and/or developmental disabilities and their families.

### *Issue*

People with intellectual and/or developmental disabilities and their families often have a hard time finding and coordinating the services, supports and resources they need to ensure a high quality of life and full inclusion in the community. Service systems can be complex, challenging to navigate and are often critically underfunded. Determining funding sources for necessary services can be extremely difficult.

In many areas of the country, resources for support coordination, also referred to as service coordination, are limited or have restrictive financial or diagnostic eligibility criteria. Some support coordinators have large “caseloads” with more people than they can fully serve. There may be high staff turnover. Support Coordinators may not be aware of universal and natural support systems that are available to all citizens.

### *Position*

People with intellectual and/or developmental disabilities and their families must have ongoing access to effective, responsive, affordable, reliable, and culturally appropriate individual service coordination as needed.

As support coordinators help design, coordinate, and monitor supports and services, they must:

- Follow the wishes and needs of each individual through a person-centered planning process;
- Enable people to explore a full range of options, to include provider options, then identify and access appropriate services and supports;
- Develop formal and informal supports (i.e., circles of support) around the individual rather than try to fit the person into existing services because of availability. Informal supports are natural supports such as family, friends, co-workers, and neighbors;
- Represent and advocate for the interests, preferences and dreams of the individual and, when appropriate, the family;
- Assist individuals and families in independently coordinating their own supports and services if they so desire, and in hiring someone of their choice;
- Be free from conflicts of interest;
- Support the development and expression of self-determination and self-advocacy; and
- Share information about desired supports and services as well as system gaps with funders so that systems become more responsive to people’s desires and needs. Support coordination must be funded at a level that supports an appropriate caseload. Support coordinators must be provided with ongoing skills development; opportunities to build capacity through peer networks; and equipped with up to date, unbiased knowledge of community resources.

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